



Factors contributing to the stigma of epilepsy

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KEYWORDS

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Coping

Summary

Purpose: To evaluate the factors, including personality and coping styles, likely to be influential in enhancing the social stigma of epilepsy.

Methods: Data were collected from 400 adults with epilepsy recruited from 10 epilepsy centers in Korea. Clinical information about seizures was obtained by neurologists, and other information was collected from self-completed questionnaires, including those measuring stigma scales.

Results: Thirty-one percent of people with epilepsy felt stigmatized by their condition and in 9% of these the stigma was severe. Multivariate analysis identified experiences of actual discrimination from society, introverted personality, problem solving controllability, and emotional subscale of QOLIE-31 as being independently associated with the social stigma of epilepsy.

Conclusions: Episodes of discrimination, coping strategies, and personality may be important in feeling the stigma of epilepsy. These findings may provide a basis for further studies to clarify the causative factors generating the stigma of epilepsy.

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Introduction

Stigma has been conceptualized as “an attribute that is deeply discrediting”.¹ The stigmatizing nature of epilepsy and its associated psychological distress have been reported to have a significant impact on the quality of life of individuals with epilepsy; however, the degree of the felt stigma and its consequences are not equal in every indi-

vidual with epilepsy.² The factors influencing the development and maintenance of feelings of stigma are not fully known.^{3,4} Seizure frequency is considered a factor significantly related to felt stigma.^{5–7} People with well-controlled seizures were less likely to express feelings of stigma if they had been seizure-free for 6 months, but even individuals with infrequent seizures had higher scores on the stigma scale compared with seizure-free patients and 14% of those who were seizure-free for at least 2 years reported feelings of stigma.³ A recent multivariate analysis showed that impact of epilepsy, age of onset, country of origin, feelings about life, and

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injuries associated with epilepsy were significantly related to scores on the stigma scale, but seizure frequency was not.⁴

The methods by which individuals with epilepsy cope with their disorder are complex and as yet relatively under-researched.⁸ An individual's personality and problem solving style, which have not been evaluated with regard to the stigma of epilepsy, may have importance in developing and/or maintaining the felt stigma. Stable personality traits are important, and a person with a more introverted personality may be more vulnerable to trivial emotional stress and may experience more negative effects than a more extraverted individual.^{9,10} In addition, problems have been found to be strongly related to psychological symptomatology,¹¹ in that daily problems can lead to psychological distress and poor quality of life.¹² These problems may have a different degree of impact depending on the problem solving style of each individual. We hypothesized that persons with a predisposition to stress vulnerability would be more affected by trivial stress and would be less able to appropriately cope with their chronic illness. The purpose of our study was to investigate whether an individual's personality or problem solving style was related to the felt stigma of epilepsy.

Methods

Subjects

Individuals aged 19–65 years, who had been diagnosed with any type of epilepsy for a minimum of one year, and who were seizure-free for the previous 24 h, were recruited from 10 epilepsy centers in Korea. Subjects were excluded if they had focal neurological deficits, progressive neurological disorders, or active psychiatric or medical disorders that would impair their judgment or have a negative impact on their quality of life beyond the effects caused by epilepsy. Subjects were also excluded if their regimen of antiepileptic drugs had been changed during the past month, if they had brain surgery during the past year, or if they used a concomitant medication with central nervous system effects. Written informed consent was obtained from all subjects.

Data collection

All subjects were asked to fill out questionnaires on the day they visited their neurologist at the outpatient clinic. Those who agreed to participate were seated by themselves or with accompanying rela-

tives in a quiet room. Subjects rated the questionnaires in person, and the completed questionnaires were checked for missing values. Demographic and clinical data were collected by interviews and from information in their medical files. Seizure-related variables included age at seizure onset, epilepsy classification, duration of epilepsy, seizure frequency, number of antiepileptic drugs, and history of seizure-related injuries (burn, head trauma, teeth injury, and others) in the previous year.

Questionnaires

Stigma scale

Felt stigma was assessed using a scale developed originally to measure patients' perception of the stigma of stroke and that was subsequently adapted for epilepsy.³ Each of the three items requires a simple yes/no response. Subjects were asked to say whether, because of their epilepsy, they felt that other people were uncomfortable with them, treated them as inferior, and preferred to avoid them. Patients scored one for each item with which they agreed. Their overall score was the sum of their positive responses. Thus, the higher the score is, the patient is more likely to feel stigmatised.

Self-esteem scale

We administered the Rosenberg Self-esteem Scale, which is composed of 10 items, 5 positive and 5 negative and scored on a 4-point Likert scale.¹³ The Cronbach alpha coefficient of this scale was 0.83.

Eysenck Personality Questionnaire

We used the Korean version of the Eysenck Personality Questionnaire¹⁴ short-form, which is composed of 48 items, consisting of four scales (psychoticism, extraversion-introversion, neuroticism, and lie) with 12 items each. The Cronbach alpha coefficients for these four scales were 0.67, 0.81, 0.84, and 0.81, respectively.

Problem solving style

We used the Korean version of the Problem Solving Style,¹⁵ which is composed of 24 items in six scales, helplessness (alpha = 0.73), problem-solving control (alpha = 0.58), creative style (alpha = 0.73), problem-solving confidence (alpha = 0.72), avoidance style (alpha = 0.62), and approach style (alpha = 0.71).

Hospital anxiety and depression scale

This scale consists of 14 items, 7 related to anxiety and 7 related to depression. Each item has a 4-point response set, ranging from 0 for no distress to 3 for significant distress.¹⁶ Individuals are identified as

not clinically depressed/anxious (total score on each sub-scale < 8), borderline depressed/anxious (score 8–10), or clinically depressed/anxious (score ≥ 11). The Cronbach alpha coefficients were 0.82 for anxiety and 0.77 for depression.

The QOLIE-31

We completed the adaptation of the QOLIE-31¹⁷ into a Korean version,¹⁸ which consisted of subscales for seizure worry (alpha = 0.86), overall QOL (alpha = 0.69), emotional well-being (alpha = 0.68), energy-fatigue (alpha = 0.62), cognitive functioning (alpha = 0.85), medication effects (alpha = 0.82), and social functioning (alpha = 0.81). Higher scores in the QOLIE-31 are indicative of a better QOL.

Questionnaire for episodes of discrimination against people with epilepsy

Subjects were asked to say whether, because of their epilepsy, they experienced actual discrimination in their daily life from other people. The questionnaire consisted of 10 items, three job-related (getting a job, being treated unfairly at work, and getting fired), 3 related to discrimination by members of the opposite sex (being rejected from dating, getting separated or divorced, or being treated unfairly by a spouse), and 4 related to friends, neighborhood acquaintances, and close relatives (being shunned or avoided, being refused a meeting, being broken off from a meeting, and being insulted). Each item required a simple yes/no response. Subjects scored one for each item with which they agreed, and their overall score was the sum of their positive responses. Higher scores indicate more episodes of discrimination experienced by each subject.

Statistical analyses

Data were analyzed by SPSS version 10.0. All independent variables were correlated with the dependent variable: the presence or absence of stigma of epilepsy as assessed by the stigma scale. The chi-square test was used for univariate analysis of these categorical variables: gender, seizure remission, seizure frequency, type of epilepsy, nocturnal tendency of seizure recurrence (more than 90% of seizures during sleep), medical treatment (monotherapy or polytherapy), history of generalized tonic-clonic seizures, history of seizure-related injuries, level of education, marital status, economic status, and employment. Student's *T*-test and the Pearson correlation test were used to evaluate these continuous variables: age at seizure onset, age at surgery, duration of epilepsy, episodes of actual discrimination, and scores on the QOLIE-

31, Eysenck Personality Questionnaire, Problem Solving Style Questionnaire, Self-esteem Scale, and Hospital Anxiety and Depression Scale. Multivariate analysis using logistic regression was performed on variables that were significant ($p < 0.05$) in univariate analysis.

Results

Subject characteristics

Demographic and clinical characteristics of the 400 subjects in the study are shown in Table 1. There were 204 men and 196 women, of mean age 32.9 years (range 19–64 years). About 89% of patients had symptomatic or cryptogenic partial epilepsy. About 20% of the participants had been seizure free for at least 2 years, with 14% having fewer than one seizure per year, 45% having 1–11 seizures per year, and the remaining 21% having one or more seizures per month. About 43% had generalized seizures in the previous 2 years, and about 9% had sustained injuries directly associated with their seizures. With regard to antiepileptic drug regimen, 55.5% were on polytherapy and 44.5% were on monotherapy.

Felt stigma of epilepsy

About 31% of the study participants reported feelings of stigma, with 9% answering “yes” to all three items, indicating that they felt highly stigmatized by their disorder (Table 2).

Univariate analyses showed that several variables were significantly associated with the presence of stigma of epilepsy, including high seizure frequency ($p < 0.01$), a history of generalized tonic-clonic seizures ($p < 0.05$), low level of education ($p = 0.001$), and a history of seizure-related injuries ($p < 0.001$). Higher scores on the stigma scale were significantly correlated with longer duration of epilepsy ($r = 0.144$, $p < 0.01$), more episodes of discrimination ($r = 0.444$, $p = 0.000$), lower scores on the QOLIE-31 ($r = -0.408$, $p = 0.000$), more introverted ($r = -0.196$, $p = 0.000$) or more neurotic ($r = 0.288$, $p = 0.000$) personality, a greater degree of helplessness ($r = 0.201$, $p = 0.000$) or a lower degree of problem-solving control ($r = -0.275$, $p = 0.000$) and problem-solving confidence ($r = -0.141$, $p = 0.000$), higher degrees of anxiety ($r = 0.278$, $p = 0.000$) and depression ($r = 0.300$, $p = 0.000$), and a lower degree of self-esteem ($r = -0.312$, $p = 0.000$) (Tables 2 and 3). Other variables were not significant, including sex, age, age at onset, type of medical treatment, type of epilepsy, timing of seizure occurrence, economic status, marital status,

Table 1 Demographic and clinical features of 400 Korean epileptics.

Gender (M/F)	204/196
Age (year)	32.9 (19–64)
Age at onset (year)	19.7 (1–61)
Duration (year)	13.2 (1–44)
Medical treatment	
Monotherapy	222 (55.5%)
Polytherapy	178 (44.5%)
Epilepsy type	
Idiopathic generalized	34 (8.5%)
Crypto/symptomatic partial	355 (88.8%)
Undetermined and others	11 (2.8%)
Seizure frequency	
Remission	81 (20.3%)
<1/year	56 (14.0%)
1–11/year	180 (45.0%)
≥1/month	83 (20.8%)
Generalized tonic clonic seizures in the last 2 years	
Presence	173 (43.3%)
Absence	224 (56.0%)
Missing value	3 (0.8%)
More than 90% of seizures during sleep	
Yes	49 (12.3%)
No	344 (86.0%)
Missing value	7 (1.8%)
Injuries in the last year	
Yes	35 (8.8%)
No	359 (89.8%)
Missing value	6 (1.5%)
Marital status	
Married	179 (44.8%)
Unmarried	188 (47.0%)
Others	21 (5.3%)
Missing value	12 (3.0%)
Employment status	
Employed	174 (43.5%)
Unemployed	75 (18.6%)
Housewife/student	141 (35.3%)
Missing value	10 (2.5%)
Education status	
Primary or middle school	88 (22.0%)
High school	177 (44.3%)
University	134 (33.5%)
Missing value	1 (0.3%)
Economic status	
High	43 (10.8%)
Middle	205 (51.3%)
Low	130 (32.5%)
Missing value	22 (5.5%)

Table 2 Social stigma of epilepsy and its relationship to categorical variables.

	Scores on stigma scale				p value
	0	1	2	3	
Total patients	69.2 ^a	13.3	8.5	9.0	—
Gender					
Male	70.1	12.3	8.3	9.3	0.790
Female	68.4	14.3	8.7	8.7	
Seizure remission					
Yes	79.0	12.3	4.9	3.7	0.046
No	66.8	13.5	9.4	10.3	
Seizure frequency					
<1/year	77.4	13.1	5.8	3.6	0.009
1–11/year	68.3	13.9	7.8	10.0	
>1/month	57.8	12.0	14.5	15.7	
Generalized tonic clonic seizures in the last 2 years					
Yes	62.4	13.3	10.4	13.9	0.013
No	74.6	12.9	7.1	5.4	
Timing of seizure recurrence					
Nocturnal	75.5	14.3	6.1	4.1	0.392
Not nocturnal	68.3	13.4	8.4	9.9	
Treatment					
Monotherapy	72.5	13.1	8.1	6.3	0.140
Polytherapy	65.2	13.5	9.0	12.4	
History of injuries in the last year					
Yes	31.4	14.3	14.3	40.0	0.000
No	73.0	12.8	8.1	6.1	
Epilepsy type					
Simple partial	73.6	7.5	11.3	7.5	0.643
Complex partial	68.1	14.5	8.9	8.5	
Idiopathic generalized	64.7	17.6	5.9	11.8	
Discrimination					
Experienced	52.9	14.8	14.2	18.1	0.000
Not experienced	80.1	12.1	4.9	2.9	
Education level					
Primary/middle school	53.4	12.5	18.2	15.9	0.001
High school	73.4	14.1	3.4	9.0	
University	73.9	12.7	9.0	4.5	
Economic status					
High	79.1	9.3	9.3	2.3	0.057
Middle	72.2	11.7	8.8	7.3	
Low	62.3	15.4	7.7	14.6	
Marital status					
Single	68.6	11.2	11.7	8.5	0.467
Married	72.6	14.5	5.6	7.3	
Employment status					
Unemployed	61.3	12.0	9.3	17.3	0.060
Employed	74.1	10.9	9.2	5.7	

^a Data in table represent the calculated percentages on numbers in brackets.

Table 3 Relationships of social stigma of epilepsy to various parameters.

	Not stigmatised		Stigmatised		<i>p</i> value
	Mean	S.D.	Mean	S.D.	
Age (year)	32.6	9.4	33.5	10.0	0.375
Age at onset (year)	20.1	10.3	18.7	10.1	0.209
Duration of epilepsy (year)	12.6	8.7	14.7	10.3	0.050
Number of AEDs	1.4	0.5	1.5	0.5	0.114
Total score on QOLIE-31	63.1	15.8	49.7	18.0	0.000
Seizure worry	63.3	15.8	49.7	18.0	0.000
Overall QOL	58.8	16.0	49.2	21.2	0.000
Emotional	63.2	18.0	53.9	19.1	0.000
Energy/fatigue	50.1	19.9	40.5	19.5	0.000
Cognitive	74.4	19.6	61.4	22.9	0.000
Medication effects	61.4	28.8	49.0	26.9	0.000
Social	68.2	23.2	50.5	25.4	0.000
Eysenck Personality Scale-Adult					
Psychoticism	1.8	1.7	1.9	1.7	0.557
Introversion/extraversion	5.8	3.2	4.6	3.2	0.000
Neuroticism	5.8	3.5	7.8	3.1	0.000
Lie	6.6	2.8	6.4	2.9	0.541
Problem solving style					
Helplessness	9.8	2.8	10.8	3.2	0.004
Controllable	12.1	2.7	10.5	3.1	0.000
Creative	12.5	2.9	12.6	3.3	0.746
Confidence	12.4	2.6	11.6	2.8	0.007
Avoidance	10.1	2.8	10.2	3.0	0.877
Approach	13.0	2.7	12.4	3.1	0.051
Hospital Anxiety and Depression Scale					
Anxiety	8.0	3.8	10.0	4.0	0.000
Depression	5.3	3.4	7.4	3.9	0.000
Self-esteem Scale	28.0	4.2	25.6	4.4	0.000
Degree of discrimination	0.8	1.4	2.0	2.3	0.00

S.D., standard deviation; AEDs, antiepileptic drugs; QOL, quality of life.

employment status, the psychoticism and lie subscales on the Eysenck Personality Questionnaire, and problem-solving creative, avoidance, or approach style.

Logistic regression analysis revealed that several factors were independently associated with feelings of stigma, including experience of actual discrimination ($p = 0.005$; odds ratio (OR) = 1.3 [95% CI = 1.1–1.6]); introverted personality ($p < 0.05$; OR = 0.9 [95% CI = 0.8–1.0]); problem solving controllability ($p < 0.05$; OR = 0.9 [95% CI = 0.8–1.0]);

and emotional subscale of the QOLIE-31 ($p < 0.05$; OR = 1.0 [95% CI = 1.0–1.1]) (Table 4).

Discussion

In our study, 31% of the participants reported feeling stigmatized by their epilepsy, 9% of them highly so. This contrasts with the findings of a recent European study,⁴ which reported that 51% of participants reported feeling stigmatized, 18% highly so.

Table 4 Multivariate analysis of significant factors associated with social stigma of epilepsy.

Factors	Odds ratio	95% CI	<i>p</i> value
Discrimination from society	1.31	1.09–1.59	0.005
Introverted personality	0.89	0.80–0.98	0.024
Problem solving control	0.87	0.76–0.99	0.038
Emotional subscale of QOLIE-31	1.03	1.00–1.07	0.046

CI, confidence interval.

Significant cross-cultural differences were noted between levels of stigma reported by people with epilepsy across Europe, with Spanish respondents reporting the lowest levels, and French respondents the highest. Our result of 31% was similar to that of Spanish respondents. We found this percentage to be unexpectedly low, based on the observation that stigmatization and psychological problems for people with epilepsy are more common in developing countries^{19,20} and based on the more negative public attitude toward epilepsy in Korean society^{21,22} compared with Western societies.^{23,24} The reason for the low level of stigmatization observed here need to be explored.

We found that 21% of individuals with epilepsy in remission for a minimum of two years reported feelings of stigma, suggesting that factors other than those related to seizures are important in generating and maintaining the stigma of epilepsy. Our logistic regression analyses revealed that experiences of actual discrimination, introverted personality, problem solving controllability, and emotional subscale of QOLIE-31 were independently correlated with feelings of stigma.

About 44% of the participants in our study reported having suffered some form of discrimination due to epilepsy, and about 50% of those who had experience of discrimination said they felt stigmatized. The proportion who felt highly stigmatized was six times higher in those who experienced discrimination than in those who did not. In proposing a sociopsychological model for the stigma of epilepsy, employment discrimination was emphasized as a cause of stigma.²⁵ In contrast, felt stigma of epilepsy was found to have no direct relationship to episodes of discrimination (enacted stigma) against people with epilepsy.²⁶ In Scambler and Hopkins' study,²⁶ felt stigma was far more prevalent than enacted stigma. The authors commented that the simple experience of being discriminated did not necessarily make individual patients feel shameful that they have epilepsy. This was supported by findings that only 3% of unemployed individuals with epilepsy cited epilepsy as the cause, whereas 32% of subjects believed that their epilepsy made it more difficult for them to get a job.³ These inconsistent results regarding the relationship between felt and enacted stigma may be related to significant cross-cultural differences in public perceptions and attitudes towards epilepsy and people with epilepsy. The perception of the general public towards epilepsy has been much more negative in Korean society^{21,22} than in Western societies.^{23,24} About 15% of the participants in our study reported having been refused a job because of their epilepsy. When they revealed their epilepsy to their prospective

employers, however, this figure rose to 55%. In a 1996 survey in Korea,²² 58% of the members of the general public surveyed said that individuals with epilepsy should not be employed as would a normal person. Consequently, most Koreans with epilepsy have tried to conceal their condition. We found that about 75% of the individuals in our survey never disclosed their disease when applying for a job.

People with epilepsy are generally considered to be at greater risk of psychopathology than those without the disorder. Increased levels of anxiety and depression^{3,5,27} and poor self-esteem^{28,29} have been reported to be common psychological problems in people with epilepsy. This psychological dysfunction was also known to be associated with the stigma of epilepsy. This is in good agreement with our results of univariate analyses. Also the emotional subscale of the QOLIE-31, which represented the psychological domain, was independently associated with feelings of stigma in our multivariate analysis. Although it is still not known whether feelings of stigma due to epilepsy are precursors to the development of additional psychosocial problems,^{30,31} it is evident that the psychological dysfunction in people with epilepsy has the significant impact on their quality of life.

Our study population was taken from epilepsy centers throughout Korea and did not include people with epilepsy spread throughout the population. Due to this sampling bias, some of our data, including those related to the prevalence of the stigma of epilepsy, cannot be generalized to people with epilepsy throughout Korea. Our results regarding the factors likely to be influential in the stigma of epilepsy, which was the main focus of this study, may be generally applicable to people with epilepsy, although these results should be interpreted with some caution.

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Appendix A

The Korean QoL in Epilepsy Study Group comprised the following: Sang-Ahm Lee, M.D. (P.I.). Hee-Jung Yoo, Ph.D.: University of Ulsan College of Medicine (Seoul); Kyoung Heo, M.D., Sung-Soo Lee, M.D., and Byung-In Lee, M.D.: Yonsei University College of Medicine (Seoul); Hyung-Kook Park,

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